

Fact Sheet: Summary of Self-Determination

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What Self-Determination Is and What it Is Not

- Self-Determination is NOT a model or a program with a predetermined menu of available services and a set way of delivering them.
- Self-Determination IS a process that differs from person to person according to what each individual determines is necessary and desirable to create a satisfying and personally meaningful life. Persons with disabilities no longer have to receive services as determined by the traditional model. They are free to "order off the menu," including those services they desire to be provided in ways that meet their needs.
- Self-Determination is both person-centered and person-directed. It acknowledges the rights of people with disabilities to take charge of and responsibility for their lives. In Self-Determination, the individual, not the service system, decides where he or she will live, and with whom; what type of services he or she requires, and who will provide them; how he or she will spend his or her time, which may include the type of vocational or educational opportunities he or she wishes to engage in, and how he or she will relate to the community, which may include joining in community events, taking part in civic groups, and developing and maintaining relationships with others in the community.

The Principles of Self-Determination

- Freedom - The ability for an individual together with freely chosen family and friends to plan a life with necessary support rather than purchase a program.
- Authority - The ability for a person with a disability (with a social support network or circle if needed) to control a certain sum of dollars in order to purchase services.
- Autonomy - The arranging of resources and personnel-both formal and informal-that will assist an individual with a disability to live a life in the community rich in community affiliations.
- Responsibility - The acceptance of a valued role in a person's community through competitive employment, organizational affiliations, spiritual development, and general caring of others in the community, as well as accountability for spending public dollars in ways that are life-enhancing for persons with disabilities.

(From: Thomas Nerney and Donald Shumway, *Beyond Managed Care: Self-Determination for Persons with Disabilities*, September, 1996).

Values Supported by Self-Determination

- Respect - Self-Determination, by its nature, recognizes that persons with disabilities are valuable, capable persons who deserve to be treated with respect. Respect is more than politeness and paying lip service. It is acknowledging the individual's value as a person, seeing his or her strengths and abilities, granting him or her the same consideration we each desire, and holding him and her in esteem.
- Choice - Choice is central to Self-Determination. Many times people with disabilities have very limited choices. They often cannot choose very important aspects of their lives, such as where they live, with whom, how they will spend their time and their money, and sometimes even what they eat. At other times, selections are limited. For instance, individuals may be able to choose who their roommate will be, but not whether or not they will have one. True choice is being able to pick from the same wide variety of lifestyles, goals, and individual preferences most people enjoy.
- Ownership - Self-Determination not only supports persons with disabilities to have more choices in their lives, but ownership of their lives. Ownership implies more than just decision-making. It means that the individual is the final and total authority-the boss. While most people are supported in the decision-making process by a circle of support, Self-Determination gives the person the final say. Ownership allows him or her control over his or her life and services. He or she may hire, manage, and if necessary, fire those who provide services. It also gives him or her control over the management of his or her

financial affairs. Ownership also means that the individual accepts the responsibility for his or her actions and decisions, including spending public monies conservatively.

- Support - Support is a keystone to making Self-Determination work. Most people have some type of support network in their lives that they turn to when they must make an important decision or take a step forward in their lives. Persons with disabilities are no different. However, before Self-Determination, those persons who helped establish goals and devise plans were mostly paid workers who in many instances were assigned rather than chosen. In Self-Determination the individual selects and invites each member of his or her circle of support. They can be family members, friends, people from the community-anyone that the person desires. Most importantly, they are people with whom the individual has or wishes to build a trusting relationship.
- Opportunity - Many persons with disabilities have had only limited opportunities to experience many aspects of life. Self-Determination expands those opportunities allowing and encouraging individuals to explore the possibilities that are present in their communities. Since they are able to spend their funds in ways that they now choose, they are able to take part in events and activities that previously were unavailable. When someone has had limited experience, it may be difficult for others to allow him or her to take risks. However, opportunity also includes the ability to take risks, to make mistakes, and to grow from them.

Self-Determination Calls for a System Shift

If Self-Determination is going to be successful, it requires that those who supply services and fund them make certain changes in both the way they think about persons with disabilities and the way they serve them. Without a shift in the service system, no philosophy can truly support persons with disabilities to become self-determining individuals. In order for Self-Determination to happen, the system must shift:

- From seeing persons with disabilities as having limitations that prevent them from participating fully in life to seeing them as valuable citizens who have many talents, strengths, and abilities to contribute to their communities.
- From seeing persons with disabilities as service recipients to seeing them as individuals with rights and entitlements.
- From providing agency-controlled services to supporting person-directed services.
- From systemic and agency control of financial resources to individual control.
- From control to empowerment.

A Final Thought

"Self-Determination is what life is all about. Without it, you might be alive, but you wouldn't be living-you would just be existing" (M. Kennedy, "Self-Determination and Trust: My Experiences and Thoughts," In Sands & Wehmeier, *Self-Determination Across the Life Span*, 1996, p. 48).

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